



## **Submission to the Welsh Parliament Health, Social Care and Sport Committee from the Rare Autoimmune Rheumatic Disease Alliance**

### **Inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales**

#### **About RAIRDA**

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) is a coalition of charities which campaigns for better care for people living with these conditions. It aims to raise the profile of this group of conditions, influence policy and guide future research.

The following charities are members of RAIRDA:

- LUPUS UK
- Vasculitis UK
- Scleroderma and Raynaud's UK
- British Sjögren's Syndrome Association

Rare autoimmune rheumatic diseases (RAIRDs) are characterised by a person's immune system becoming dysfunctional and attacking its own healthy cells, leading to inflammation and damage in tissues and organs which is often irreversible and can be potentially fatal. These conditions can affect many parts of the body (including joints, skin, lungs, kidneys, and heart) and often require cross-specialty medical expertise. Unlike many other rare diseases, these conditions predominantly occur in adult life and do not have a simple genetic link. They also disproportionately affect women – for example women make up 80% of people who have lupus. The impacts of these conditions vary from person to person depending on the organ or organs affected but they can be severely life-limiting and potentially life-threatening. Around 9,000 people will be diagnosed with one of vasculitis (including Behçet's), scleroderma, lupus or primary Sjögren's syndrome every year in the UK.

#### **Summary**

From Monday 27<sup>th</sup> April to May 14<sup>th</sup> RAIRDA surveyed UK patients on their experiences during the Covid-19 pandemic, including how it had affected the care they received for their condition. Over 1,000 responses were received from across the UK<sup>1</sup> with 87 from people with RAIRDs in Wales.

Well over half of RAIRD patients who responded to our survey are currently shielding, meaning it is particularly important that we balance the need to monitor and treat patients' RAIRD conditions with the need to protect them from Covid-19.

Patients in Wales were less likely to report a change or disruption to their care compared to the rest of the UK, however when there was a change they were more likely to say that changes to their care had impacted their ability to manage their condition.

The three most common changes people reported were:

- Appointment cancellations
- Having appointments by virtual or telephone link rather than in-person
- A reduction in blood monitoring tests.

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<sup>1</sup> The full UK report is available at: [rairda.org/our-reports/](https://rairda.org/our-reports/)

Of these, cancellations were most strongly linked to patients feeling their ability to manage their condition had been adversely impacted as a result of changes. People who had moved to virtual appointments were slightly less likely to say changes had impacted their ability to manage their condition.

Failures to manage these conditions can have consequences for patients as well as the health service, as more expensive treatments are required to manage preventable organ damage. As the health service enters a stage of 'recovery' the health service should prioritise allowing patients to raise issues like flares of their condition early and making sure that no patient experiences an unsafe gap between monitoring appointments.

### **Monitoring tests**

Monitoring tests are essential to detect potentially asymptomatic, but irreversible, organ damage that can be caused by disease course or medication side-effects. 19.5% of respondents from Wales stated that the frequency of their blood tests had been reduced, lower than those of England and Scotland (25.1% and 21% respectively). The highest proportion of Welsh respondents stating this change were those with lupus, at 50%, falling to 29.2% for respondents with vasculitis and 5.3% with scleroderma. 41.2% of those who said yes to this first statement found that this change had contributed to a change in their ability to manage their condition. Failure to detect these issues early will lead to more patients requiring expensive treatments like dialysis. It is therefore in patients' and the health service's interest to minimise the risks associated with long monitoring intervals. Some areas of the UK have started to deliver these monitoring tests for patients at home, but this is not universal. Some tests, such as urinalysis, cannot be administered remotely.

*"I received no advice regarding my blood monitoring test. Eventually had to arrange for district nurse to visit for these."*

### **Cancellations**

35.6% of Welsh respondents had one or more appointment cancelled, and 41.4% had an appointment that would have been in person take place over telephone or video-call. 64.5% of those who had appointments cancelled said that their ability to manage their condition had changed because of disruption to their care. This is likely because they are not being provided with an opportunity to discuss any progressions in their condition or issues with medication. However, there is an evident impact of not being able to physically be in the presence of a medical team, as illustrated by the 44.4% of respondents who found that their ability to manage their condition had altered, despite still being able to have a verbal check-in with their doctors and discuss issues. One limitation of virtual appointments is the lack of physical monitoring tests mentioned previously. 100% of Welsh respondents living with lupus had one or more appointment cancelled, compared to 52.6% of patients with scleroderma and 29.2% of patients with vasculitis; overall, we're concerned this means there is a considerable number of individuals who may suffer from the long-term consequences of not having their routine medical appointments.

*"Have just started taking Methotrexate by injection but no longer having blood tests which should have been done every 2 weeks."*

*"I have had my hospital appointments postponed indefinitely which I understand completely but I have had no shielding letter, no contact from the GP or Consultants, no advice or guidance. I feel forgotten, neglected, and uncared for."*

### **Other changes**

4.6% of respondents from Wales had been offered a regular appointment in an alternative location, with 50% of this group stating that this was a contributing factor to changes in their ability to manage their care. 100% of Welsh respondents with lupus noted this change in their care provisions, whereas only 5.3% of those with scleroderma and none with vasculitis had attended an appointment at another setting. For many individuals, the appointment will have taken place in their GP clinic, which may be beneficial for them as it will enable them to receive care closer to home rather than having to travel, often hundreds of miles, to a hospital with a rheumatology department, which can be both time-consuming and costly. We've previously found that over half of RAIRD patients are not confident in

their GP's knowledge of their condition<sup>2</sup>. This shows why the switch to care from GPs has been relatively small and highlights that these services cannot substitute for specialist care.

### **No reported changes**

32.2% of Welsh respondents had no reported changes. This is higher than the overall proportion in the UK, where an average of 20% said they had experienced no change in care plans.

### **Conclusion**

48.2% of respondents from Wales stated that the change(s) to their care had affected their ability to manage their condition. This was the highest of the 4 devolved nations (England – 39.2%, Scotland – 37.7%, Northern Ireland – 38.1%). This indicates that while the measures taken by hospital teams to protect both patients and themselves from Covid-19 have been important, they have hampered the ability of people with RAIRDs to manage their conditions appropriately.

Patient care was also impacted by the need to redeploy medical staff to deal with Covid-19. This issue was likely compounded by the issues present prior to the pandemic surrounding rheumatology care in Wales, particularly a shortage of rheumatologists. This shows the importance of addressing these longer-term issues to not only deal with the backlog of cases and appointments that now exist, but also to ensure good quality care in the long term.

*"I feel that I have completely fallen through the net. When I attended A&E and was given a provisional diagnosis and I was told I needed to see a rheumatologist asap. There was no rheumatologist for me to see due to staffing shortages. Since then my condition has been managed by my wonderful GP who is doing her best but admits herself that she feels exposed as my condition normally managed by a rheumatologist... I feel very anxious and vulnerable about this situation and have no access to specialist support if I have a flare."*

Approximately 50% of people with RAIRDs are shielding. Some patients reported concerns about attending appointments due to concerns about Covid-19 infection, however many more reported issues with access to services and ability to contact clinicians with their concerns. Comments from patients indicated that where they did have concerns about safety, having the steps that would be taken to protect them from Covid-19 during appointments communicated to them offered reassurance. Due to the nature of each of the RAIRDs, it is crucial that a balance is struck between protecting patients from Covid-19 whilst also ensuring that they receive medical care for conditions which can quickly progress if not treated correctly.

*"The idea that non-covid patients are being supported & helped is not the case for myself or other people with lupus that I know."*

### **Recommendations**

- 1) Virtual or telephone appointments remain better than no appointment or contact with clinical teams at all. However, people with RAIRDs have a greater need for some in-person care and tests than other rheumatology patients due to the fact they affect internal organs and are the sometimes asymptomatic nature of complications.
- 2) Hospital teams and other care providers should prioritise effective communications with patients to allow them to understand how changes to the way in which hospitals will function in the near future will affect them, how they will protect them from Covid-19, and to agree how care plans will be conducted moving forward. This will not only help to deal with anxieties about attending appointments which patients have but it will also ensure that these people are accessing urgent care for issues like flares in a timely manner from the appropriate service.

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<sup>2</sup> RAIRDA, 2018, 'Reduce, Improve, Empower: Addressing the shared needs of rare autoimmune rheumatic diseases' Available here: <https://rairdaorg.files.wordpress.com/2020/06/rairda-survey-report-2018.pdf>